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ABSTRACT

The case study, one of a series of reports describing innovative practices in integrating people with disabilities into community life, describes the Community Training and Education (CITE) Program in Cincinnati (Ohio), which provides training and education for children with disabilities and their families through home-based services. The program is administered by a not-for-profit corporation. The first section examines the development of this new service delivery approach noting the importance of administrative leadership, creative redirection of funds, and coping with resistance from parents and from within the agency. The program is then described noting eligibility (all children with a primary disability of moderate to profound mental retardation), the referral process, services offered, parent involvement, funding/costs, and staffing. Accounts of visits to eight families served by the program are then summarized with parental reactions covering: the need for on-going rather than time-limited support; the value of services provided in their homes; help with coping skills; involvement of fathers; emotional support; and dealing with challenging behaviors. The final section identifies program issues including lack of complete agreement on the program's ideology, the dilemma between maintaining a professional distance and providing emotional support, and the definition of "family." Includes six references. (DB)

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"THE ANSWER TO MY PRAYERS":

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of the CITE Family Support Program

Cincinnati, Ohio

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"THE ANSWER TO MY PRAYERS":
A Case Study
of the CITE Family Support Program
Cincinnati, Ohio

by

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Based on a site visit
September 1, 2, & 3, 1987

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This is one of a series of reports on programs and services that support people with severe disabilities in the community. The purpose of this series is not to evaluate programs or services, but rather to describe innovative practices for integration people with disabilities into community life.

SUMMARY DESCRIPTION

The Community Integrated Training and Education (CITE) Program is a family support program providing training and education for children with disabilities and their families within the natural home through home-based services. The program was established to prevent residential placement of children and is based on the ideology that the development of children with disabilities can best be facilitated through active support of the natural family. The CITE program started in November, 1986 as a pilot program.

The CITE Program is a part of the Resident Home for the Mentally Retarded of Hamilton County (RHMR), Cincinnati, Ohio. RHMR is a not-for-profit corporation founded in 1963 by a group of parents. The largest program run by the agency is the West Fork Educational Center which provides educational and residential services for 32 children in both five-day and seven-day programs. RHMR also operates three group homes in the City of Cincinnati, two serving adults and one serving children. Each home has six residents. In addition to the new CITE program, RHMR has recently started a pilot program serving people who need emergency residential services.

THE SITE VISIT

This report is based on a three-day site visit from September 1 - 3, 1987. The focus of the visit was on RHMR's new family support program: the Community Integrated Training and Education (CITE) program which marks the first time the agency has offered home-based support services to families. Information about the CITE program was obtained through interviews and discussions with agency administrators, the program coordinator, and direct service staff, visits to and interviews with eight of the families receiving services, and a review of numerous plans, programs and agency descriptions, resource materials, and articles. The site visit also included a brief visit to two of the four residential programs run by the agency: the West Fork Educational Center and St. James, a group home for six children and adolescents. The purpose of the site visit was not to conduct an evaluation of the program or the agency, but rather, to identify and document innovative practices and good ideas for supporting children with disabilities and their families.

FAMILY SUPPORTS: THE LARGER CONTEXT

A few years back the most innovative practices in community living for children with disabilities referred to small group homes. Today, the most innovative practices are directed toward supporting families of children with severe and multiple disabilities to take care of their children at home. It was not until recently that states and local agencies began to fund support services for families (see for example, Taylor, Racino, Knoll, & Lutfiyya, 1987). At present many agencies are struggling to change their service delivery away from segregated group settings for children to more community-based family supports. Such change efforts often meet a great deal of resistance. This was also the case in Cincinnati and it took a fair amount of effort to convince people that the CITE program was a good way of serving children with disabilities and their families. One of the most important lessons of this case study is learning from the agency's struggle in creating innovative family support services in a very hostile environment.

This report has three main purposes: first, to examine the process the agency went through in creating change in service delivery; second, to describe the new family support program; and third, to examine, from the families' point of view, how the program is meeting the needs of families. The last section of the report discusses some of the issues and dilemmas the agency was struggling with at the time of the visit.

THE AGENCY

The agency, Resident Home for the Mentally Retarded of Hamilton County, is one of the oldest agencies in Cincinnati serving children with disabilities.

The History of the Agency

The agency was established in 1963 by parents who were dissatisfied with the lack of services available for their children with disabilities. The parents raised money and bought land in Cincinnati, Ohio. The farm house on the land was used for a day care center for children and plans were made to build an educational/residential center. The first building of this center, known as West Fork Educational Center, was opened in 1966. There is room for 45-47 children at West Fork, but there have never been that many children there. Most of the 32 children who are at West Fork now both go to school and live there for 5 days a week and go home on weekends. A small number of children stay 7 days a week and go home only 3 weeks out of the year. The old farmhouse now houses the agency's administrative headquarters.

In 1973 the agency opened a group home for 6 children, and in the early 1980s it added two group homes for adults, each for 6 people. All the group homes, or "family homes" as the agency calls them, are located in ordinary neighborhoods in Cincinnati.

The CITE program, which started in November 1986, is a part of the agency's attempt to develop a more integrated way of serving children and their families and reflects a commitment to provide the best services possible. The agency's newest

program, Emergency Residential Services, is another example of this same attempt. It was started in 1987 and is a pilot program established to prevent institutional placement of people with mental retardation who need emergency services because of some kind of a crisis; for example, if a parent becomes seriously ill or dies. The program provides supports within the person's home or other temporary support outside institutions, for example, in a temporary foster home.

Organizational Structure

The agency has a Board of Trustees which consists of two parents and seven professionals who have been associated with the agency for a long time. The executive director has worked for the agency for 5 years and is committed to provide state-of-the-art services and to develop more integrated ways of serving children with disabilities. The next level of administration consists of a business administrator, a director of programs, a head nurse, and a community resource specialist. A director of community living arrangements oversees the three "family homes" and each home has its own manager who is a "live in" person. In addition to the direct care staff the agency has occupational and physical therapists, communication specialists, nurses, social workers, and other specialists. The CITE program has a program coordinator and four direct care staff which the agency calls "trainers." In addition to the above there are secretaries and other administrative support staff, custodians, cooks, and people who work on building maintenance. At the time of the visit there were over 100 employees working for the agency. This includes both full-time and part-time people.

Funding

RHMR is funded both by the state of Ohio and Hamilton county. As a pilot program, the CITE program is funded exclusively by the Hamilton County Mental Retardation tax levy.

CREATING CHANGE IN SERVICE DELIVERY

Family support services are designed to assist families who wish to keep a member with a disability at home, but need assistance to do so. This agency is a part of a growing national movement which recognizes the importance of supporting families in caring for their children with disabilities at home. One of the greatest shortcomings and tragedies of traditional services is that they have undermined families. In the United States, as in so many other countries, it has often been easier for parents to institutionalize their children with disabilities, or place them in other out-of-home settings, than to receive support services to keep their children at home. Families have historically been faced with two options: either to place their children out-of-home, or to take care of the child at home, with little, or no, external assistance (see for example, Agosta, et al., 1985). There is now a growing understanding and commitment to devote more attention and resources to support families of children with disabilities to care for their children at home, and the term "family support" has become quite popular in the last few years.

Most family support programs in the United States started after 1980. In many places family support services are limited to respite services while others offer a wide range of services to meet the individual needs of each family.

Moving with the Changes in the Field

RHMR has always seen itself as attempting to provide state-of-the-art services. Today, the leaders of the agency see West Fork Educational Center as a limited program. During the past few years there has also been less and less interest in the kind of a program offered at West Fork and consequently there have been fewer and fewer referrals. In April 1986, the agency brought in two outside consultants to give them advice about how they could change the way they delivered services. One of the agency's administrators said:

> Originally our consultants recommended this type of program to us (the CITE program), both because it is a good idea and a good program to have and also because there is nothing like it in Cincinnati or really in Ohio. This state does not stress family support. So they thought that a good integrated family support program would have a teaching value, it could be a model.

But there were many hindrances on the way. The leaders of the agency did not have the funds to start the new program. The majority of the agency's staff didn't support the idea, and both parents and professionals in the Cincinnati area resisted the idea of a family support program. It was quite a challenge for the leaders of the agency to overcome these hindrances and create change in service delivery.

Administrative Leadership

Good services don't emerge on their own. For good ideas to become reality it takes administrative leadership and commitment. The administrative leadership of

RHMR took an active role in making things happen. They were committed to prevent out-of-home placements of children and provide the best services possible. But they were trying to create change under very difficult circumstances. In their attempt to move from a segregated service delivery system to a community-based approach one of their first challenges was, as one administrator described it, to convince people: "How do you convince people that something like CITE is a good way to serve children with disabilities and their families?"

How Do You Convince People?

According to the administrators of the agency, the Cincinnati area is conservative in terms of service delivery and has few innovative programs. The agency's first challenge was to convince the local Board of Mental Retardation, as well as parents and professionals in the area, that a family support program was a good way of serving children and their families. At first, when the agency tried to introduce the idea, people didn't know what they were talking about, or as one administrator said: "The special education leaders in the area really thought we were kind of crazy." The parents in the area did not support the idea either. One of the administrators explained: "The parents knew they needed help but they identified help with sending the child out-of-the-home." Initially the idea only had the support of two or three parents.

The leaders of the agency concluded that the only way to convince people was to start the program and demonstrate to people what a family support program was all about. They decided to start small and provide training and education in the

home, both for the child and the family. One of the administrators said: "When we started the CITE program we didn't intend it to be an answer to all problems. What we hoped to do was to try to get our foot in the door with something else than has been done and show some success with it."

High Level of Trust

As one of the oldest agencies in the Cincinnati area RHMR has a high level of trust among parents. It was founded by parents and is "rooted in parental concern," as one of the agency's leaders phrased it. Most of the parents I spoke with confirmed this and seemed to trust that "Resident Home" (as parents called the agency for short) would only provide good services. The agency has the reputation of working with parents and providing good services. This was the agency's major strength in gaining trust and support among parents and professionals in the area and made it easier for the agency to create change in service delivery.

Creative Redirection of Funds

Funding for the CITE program became possible due to declining enrollment at West Fork, thus enabling the agency to close one of the cottages and redirect the funds to the new family support program. This was a very debated issue and the one that created the most tension. Both agency staff and parents had, for a long time, identified "help" with out-of-home placement and feared that the new program would mean the scaling back or closing of the West Fork Educational Center.

Resistance from Parents

In the beginning many of the parents seemed to trust that the new CITE program would be a good program and provide good services. But parents resisted the intent of scaling back the program at West Fork. They did not want to replace residential services with services in the home. One of the agency's administrators told me that many of the parents had said: "The CITE program may be a good idea but that is not what we need. We need more West Fork and what you need to do is to expand the services there." Parents had learned to identify residential placement as something they needed. This was one of the greatest challenges to the leaders of the agency. The agency has always respected parents, attempted to provide services which meet the parents needs, and emphasized the importance of working with parents. The agency's point of view has been that parents know best what they need and it should not be the role of the professionals to tell parents what services they need. One of the administrators said: "We listen to parents and give them what they want."

In their attempt to create change in service delivery the leaders of the agency suddenly found themselves in a very uncomfortable situation: they were trying to create and promote services which many of the parents in the area said they didn't need and didn't want. The agency's leaders were accused of not listening to parents and being so egoistic in promoting the new program that they forgot about parents. One of the leaders of the agency said: "I was really affected by this and I wondered if I was betraying parents who really wanted more residential services." At the same time the leaders of the agency believed that parents had been "taught" to identify "help" with residential services. They also believed that parents needed help in taking

care of their children at home but because parents had never heard of home-based family support services they didn't know what to ask for.

The leaders of the agency proved to be right. After they had been serving families for a while parents changed their attitude towards the program. One of the administrators said: "Now parents are saying to us: 'We really like this type of services and we want more of this.' A year ago people weren't saying they wanted any of it. In one year now we don't think we will ever lack the support of parents for this program. Parents are nuts about it, they love it."

Resistance from Within the Agency

Closing one of the cottages at West Fork and redirecting the funds to CITE was, and still is, a very debated issue. Most agency people, including the Board of Trustees and staff, do not think that the West Fork Educational Center should be scaled down or closed.

The closing of the cottage at West Fork also created tension because the staff who used to work there didn't have a job any longer. When the cottage was closed staff could choose to be laid off or take a job in the new CITE program. While some of the staff transferred to the CITE program, the agency had to lay off one or two people. One of the administrators said: "The morale in the agency really sank for a while. We were accused of being heartless and not caring about the employees." Although many of the CITE trainers took a job in the program under these circumstances they like working for the new program. One of the trainers told me that he had been working at West Fork for one year: "I could either be laid off

or take work in the CITE program and I chose CITE." He added: "I love to work in CITE... I enjoy working with the parents and the kids."

One of the major issues within the agency now is what should be done with the West Fork Educational Center. This is an unresolved dilemma for the agency. There is not a consensus within the agency about what should be done with West Fork. One of the leaders of the agency said:

> I personally would be very happy to see the CITE program blossom and the need for a residential services out-of-the-home fall to zero. I don't think everyone here would agree with that and a lot of parents who have children at West Fork would disagree. They would accuse me of not understanding how difficult it is to have the child at home. They would tell me that there would always be families that would need a program like West Fork.

The Struggle With One's Own History

The agency has, from the start, mainly focused on serving children and for a long time it has provided services in traditional segregated group settings. One of the leaders of the agency described the agency's history in the following way:

> The funding system in Ohio, as in many other states, has always been focused on out-of-home care. If you keep your child at home you manage on your own, but if you gave the child up, then there was a support system around the child in a group home or an institution... We went along with the idea that if you wanted services for your child, you would have to give it up and send it to a group home.

The new CITE program challenges the history of the agency. The leaders of the agency have created a new integrated family support program that is competing with the agency's segregated programs.

The Future

At this point most of the people in the area agree that families both want and need a program like the CITE program. The program is no longer seen as a pilot program. It is there to stay. There is not, on the other hand, a consensus on how the program should develop in the future. It started as a flexible but narrowly focused, time-limited program. Most of the parents want the program to expand to provide on-going support and a wider variety of services. At the time of the site visit it was not clear how the program would develop; if it would continue in its present form or expand to meet the wishes of parents.

The agency is at a crucial point now. It has gained a great deal of support for the new family support program. But it has not resolved the dilemmas around what to do with its segregated residential services for children. The leaders of the agency want to move away from providing such segregated services for children and change the service delivery towards a more integrated model. The agency has plans to create more community-based services such as foster care. At the same time they are facing a great deal of resistance, both from people within and outside of the agency, people who strongly oppose the idea of changing the West Fork Educational Center.

The agency has the potential to have a great deal of influence on services in the Cincinnati area. The future of the agency, as well as the future of the CITE

program depends very much on how the agency deals with some of the problems and dilemmas it is facing today. I will return to some of these issues and dilemmas in the final section of this report.

THE CITE PROGRAM

The Community Integrated Training and Education (CITE) program is a family support program that provides training and education for children (age 6 months to 22 years) with disabilities and their families. The program started as a pilot program in November 1986 and was serving 25 children and their families at the time of the site visit. Since the program started it has served around 30 families and, at the time of the visit, there were 9 families on a waiting list.

The Goals of the Program

The agency describes the goals of the CITE program in the following way:

> The primary goal of the CITE program is to develop skills in the family. Skill development and education would first occur with the child and secondly with the parent or primary caregiver. Another goal of the program is to provide support to families who may have considered residential placement at one time, but have chosen to keep their child at home. Finally, a long-range goal of the program is to decrease and delay the need for residential placement. (RHMR, 1987, p. 2)

The same source states that approximately 64% of the CITE families have considered at one time or another the option of residential placement.

Who is Eligible for Services?

The eligibility for services is primarily determined by the funding source. The program is funded by the Hamilton County's Board of Mental Retardation which serves people who have moderate to profound mental retardation. Thus, children (age 6 months to 22 years) who live in Hamilton county and have a primary disability of mental retardation (moderate to profound) are eligible for services. Many of the children enrolled in the program also have additional disabilities such as autism, cerebral palsy, and visual impairments.

The Referral Process

Initial referrals of families can come from various other services and programs such as local hospitals and local educational agencies, pediatricians, Hamilton County Board of Mental Retardation programs, and Hamilton County CCDD Case Management. The first contact with the CITE program can also come directly from parents or other family members. In fact, program staff prefer that the initial contact is made by parents and think it is important that the first step is taken by parents. One administrator told me that he was cautious about taking referrals from outside the family because he felt it was very important to make sure the parents wanted them in the home:

> The social worker may not be reading the family correctly and it is not fair on our part or the family's part that we get into a situation where we may not be wanted. We are pretty sure that if they call us that they want us there and that will make everything else a lot smoother.

After the initial contact, program staff interview the parents to determine whether the services offered by the CITE program can meet the needs of the family. Based on this interview, the CITE coordinator and social worker meet with the parents to start discussing what the CITE program is going to work on with the family. Based on what the family asks for, an individualized service plan is developed for each family.

The Services Offered

The CITE program focuses mainly on providing training and education for both the child and other family members. The training takes place in the home or other community settings, such as restaurants, stores, swimming pools, and so on. The training is directed towards daily living skills such as eating and dressing; problematic behavior; communication skills; and other things the family needs help with. Much of the effort is directed towards helping the family deal with difficult issues which seriously disrupt the family or the child, such as sleeping problems or challenging behaviors. The assistance is time-limited or "problem-limited," as one of the administrators described it. When the program has helped the parents find a better way of dealing with the problems, program staff start pulling back and fading out.

Besides education and training, the program has also assisted families in various other ways, such as finding other services and resources. If appropriate, and if the family wishes, CITE staff may also initiate contact with the child's school program to coordinate things between the school and the home, and CITE staff have managed to get children who have been suspended from school back into school. In

many instances CITE staff also function as emotional support for the family. The trainers usually work with each family for one and a half hours each time and come into the home from once a week to five times a week. Most often the family is visited twice a week and the prime time of the program is from 4 p.m. to 8:30 p.m.

Parent Involvement

Administrators of the CITE program describe parents as partners. The program takes place in the families' home and parents are expected to participate in the child's program by watching the teaching methods used, and learning to employ those methods. Parents are strongly encouraged to participate in each step of the training process, beginning with the design of the child's program.

Funding and Costs

The CITE program is funded through a contract with the Hamilton County Board of Mental Retardation and the Board has significant influence on the structure of the program and the services offered through this contract. Services are provided to the families at no cost. The agency has compared the average costs of serving families by the CITE program with the average costs of out-of-home placement. This cost information is based on projected CITE costs between November 1986 and October 1987. The result of this study shows that CITE's average cost per family was $2,674. At the same time the average cost of serving a child in a group home was $23,462. The average cost of foster care placement for a child was $18,250 (RHMR, 1987, p. 5).

Staff

The director of programs oversees the CITE program. He takes referrals to the program, makes the initial visit to the home and participates in "staff meetings" (a meeting which takes place every 2-3 months where the parents, the trainer, and the CITE coordinator sit down to discuss how things are going). The director of programs has a strong clinical background and a master's degree in special education.

The CITE program has its own coordinator who also has a master's degree in special education and has worked for the agency for a few years. Before she became the coordinator of the CITE program she was a teacher at West Fork. The coordinator is very committed to her work: "I love my job. It is very rewarding. I'm very excited about my job and I feel like I'm doing something of importance."

The direct care staff who go into the homes are called trainers. The CITE program had five trainers at the time of the site visit. Two of them worked full-time and three part-time. All the trainers have high school education and some of them have additional years of college. None of the trainers had a degree in special education or other disability related areas. All the trainers had previously worked at West Fork or one of the agency's group homes before they started working in the CITE program. Before the CITE program started the trainers were required to attend a week long training provided by the agency. There is also on-going training on the job and the program coordinator provides support and guidance to the trainers.

In addition to the program coordinator and the trainers, the program has access to some of the specialists at West Fork as consultative staff on an as-needed

basis. This includes a social worker, behavior management specialist, communication specialist, occupational therapist, and a registered nurse.

THE FAMILIES AND THE SERVICES

The site visit included a visit to the homes of eight of the families served by the CITE program. This section describes some of these families and presents their perspective on the CITE program.

There was a significant diversity among the families I visited in terms of social, economical, cultural, and racial backgrounds. Three of the families were black and five were white. The socio-economic situation of these families ranged from very poor families living in low income neighborhoods to an upper class family living in one of the most prestigious neighborhoods in Cincinnati. Two of the families were single-mother families, the rest were two-parent families.

Despite the diversity, these families had one thing in common: they all liked the CITE program very much and had few negative or critical comments about the programs. One of the mothers said that the program had been: "... the answer to my prayers." The only common criticism of the program was that it only provided time-limited support. The families wanted the CITE program to provide on-going support. None of the parents had experienced a similar program before but thought this was an excellent way of supporting families of children with disabilities.

Time-Limited Program or On-Going Support?

The Spencer family was the first family served by the CITE program. The parents, Ellen and Richard Spencer[1] have two children, 3 year old Helen and Paul who is 7 years old and has multiple problems: mental retardation, severe seizure disorder, and behavioral problems. The Spencer family lives in a nice house in a good neighborhood in Cincinnati. The leaders of the agency sometimes refer to Ellen Spencer as "CITE's Godmother" because she has, from the start, been one of the strongest advocates for the CITE program. Ellen's support was very important, especially in the beginning when there was hardly any support for the program among parents and professionals in the area. When I asked Ellen how she became involved with the CITE program she said:

> I became involved in the program basically because I could not handle Paul's behavior. I decided I could not send him away. I just could not do it. I want to keep Paul at home. He is a part of this family. I called the Resident Home so they could maybe train Paul. A few weeks later the social worker called and said there was this program and I just went nuts. It is just insane not to have family support. The CITE program was just something that I needed. We didn't want to let go of Paul.

Ellen's main criticism of the CITE program is that it is time- limited. She and her son have now "graduated" from the program for the time being, but Ellen is on the waiting list to receive services again. She said:

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[1]All the names of individuals which appear in this case study are pseudonyms.

> I'm hoping they will come back. I know there is a waiting list but I see the need for having them back. I'm not incompetent and insecure, but I need help. I guess I can see, having Paul at home, I need some help for the rest of his life with us.

Like Ellen Spencer, most of the other parents also stated very strongly their need for on-going support. The main goal of the CITE program is to prevent out-of-home placement. From the parent's perspective, this goal can only be reached if the family receives on-going support.

A Home-Based Service

The parents agreed that one of the crucial things about the program was the fact that the program took place in their homes. The parents said it made all the difference that the trainers came to the home to help them figure out how they could carry things out on a day-to-day basis in the home. The Lepan family made this point very clear. This is a family with 3 children: Bob, 4 years old; Tim, 2 years old; and Viola, 6 months old. The mother, Anne, is a nurse but stays home to care for the children on a full time basis. Anne told me that they had received a lot of information about what to do with their son Timmy who has cerebral palsy, mental retardation, and is blind. What they didn't know was how to make all this knowledge from all these different professionals applicable to everyday situations. The CITE program gave Anne and Peter, her husband, the hands-on support to pull it all together. Or as

Anne said: "We needed this human contact and intervention that makes the difference." What they saw as critical was that the program operates in the environment where and when things naturally occur.

The fact that the program comes to the home makes it very accessible for parents, especially mothers who have difficulties going outside the home for services. Anne Lepan explained to me that one of the reasons she liked the program so much was the fact that it was hard for her to run around chasing after services because she had so many small children. She said: "This was the first resource that came to our house and that makes a lot of difference when you have little kids." One of the black single mothers made a similar point when she told me that because of her transportation problems (she can't afford a car) it made a difference that the trainer came to her home.

Helping Parents Cope

Many of the parents said that the major benefit of the program was that it helps them help their child by teaching the parents how to deal with situations in the home. One of the fathers I met, Derrick Harding, articulated this when he said that at first he had expected the program to come and fix his kid: "But they don't fix kids, they train parents to cope with problems." The Harding family had been going through a very difficult period with their 15 year old son Eric. It was mainly Eric's behaviors that were the problem. These behaviors were having a seriously negative influence on the whole family and the parents didn't know how to deal with these problems. Derrick Harding told me that there had been very positive changes in his

son's behaviors but he quickly added that the main changes were in the way he and his wife approach and deal with problems that come up: "The major changes have been in us, the parents."

Anne Lepan made the same point when she told me: "The most important thing is to work with the parents, to deal with us, the people who are going to make the change and difference with that child."

Trainers as Advocates for the Family

Instead of evaluating the family (like professionals who come into people's homes have traditionally done), the trainers tend to evaluate the service system on behalf of the family and how it is meeting the family's needs. CITE people have become critical of some of the services in Cincinnati that are not meeting the needs of families. CITE staff has also helped the families deal with the service system. For example, they have helped families gain access to information, get suspended children back into school, located other services, and financial resources. The parents have found this assistance very valuable.

One of the single-mother families I visited is a good example of how important this is for the families. This is Margaret Ryan, who is black and lives in public housing in a low income neighborhood with her three children; Joseph who is 7, and Gloria and Karen who are around 10-12 years old. Joseph is labelled autistic and has self-abusive behaviors. When the Ryan family became involved with the CITE program Joseph had been suspended from school because of his behaviors and was on home-bound instruction. Margaret Ryan told me: "The CITE program is one of the

best programs that I know of because they come into the home and help parents with the special child. It has also helped me get my son into school again." Before the CITE program helped her get Joseph back into school, Margaret was just about to give up and send Joseph away to a residential school, not because she wanted to, but because she didn't see any other alternatives. Margaret talks about her son in a very loving way and sees the CITE program as a very good program because it helped keep her son at home.

The Mother is the Main Caregiver

It is a well known fact that the mothers of children with disabilities usually have the main responsibility for caring for the child. This was the case with the families who were involved with the CITE program; the mother was the main caregiver in all of the families I visited. The mothers made the initial contact with the program and the program focuses primarily on working with the mothers. One of the mothers I talked to said: "I'm to bear the burden, he (her husband) doesn't have to carry the burden the way I bear it. He will sacrifice me for our son... I will have to stay home." Not only are the mothers the main caregivers and "educators" in the home. They are also the ones who go out to find programs, specialists, equipment, and whatever else is needed. In addition they coordinate these services, people, and activities. Another mother said: "You have to case manage the ones who are involved, there is no other way." She also told me that she found it hard to be a "case manager" because she lacked the appropriate knowledge and skills.

One of the things I was interested in learning about in Cincinnati was how much fathers were involved in the caring work around the child and whether or not the CITE program tried to encourage the fathers to participate in the program. Before the site visit I specifically asked to meet families where the father was involved. Because of this purposeful selection of families, the level of fathers' involvement found among these families is probably higher than fathers' involvement in general.

Helping Fathers Become Involved: The Mothers' Point of View

The CITE program does not have a clear policy about involving fathers but is happy to work with them if the fathers themselves want to be involved.

All the mothers in the two-parent families I visited were eager to have their husbands become involved with the program and saw the program as an opportunity to involve them. Many of the mothers saw themselves as having succeeded in this. In this context they saw it as crucial that the trainers could come into the home outside regular working hours, when the fathers were at home. Some of the mothers said that the program had not only helped the fathers become more involved with their child, it had also helped the fathers become involved with the child in a different way. Anne Lepan said about the CITE program: "It helped to get Peter (her husband) involved. It helped him to have a relationship with Timmy. I think he had a relationship with Timmy from the beginning but I think it wasn't a hopeful

involved relationship." Anne Lepan also said that the CITE program had helped the relationship between her and her husband because her husband was now able to understand: "... the importance of me nagging about teaching Timmy."

One of the mothers I talked to expressed her disappointment that her husband did not want to become involved in the program.

Helping Fathers Become Involved: The Fathers' Point of View

During the visit I met three fathers who were all considered, by the agency, to be very involved with their children and the CITE program. One of these fathers said that the CITE program had given him an important opportunity to become more involved with his son:

> The CITE program helped me work with Timmy. (The trainer) taught me how to relate to him. It gave me the confidence of working with him, spending time with him, and knowing how he interacts best. If it hadn't been for the CITE program I would probably not have this relationship with Timmy.

Another father, who said he had always been very involved with his daughter, said that he and his wife had asked for evening sessions so that he could stay involved, "I would not be able to carry it over if I'm not there to see how it has been," he said.

The third father said that he was very involved with his sons and the CITE program had helped him stay involved. He said it had been helpful that the trainer came after work hours because if the program only took place during the day he would be getting second hand information.

These fathers were grateful for the program's efforts to involve them.

Help to Lead a More Normal Family Life

Many of the parents said that the CITE program had helped them lead a more normal family life; both within the home and outside the home. Some of the families had, for example, serious problems eating together as a family because of the child's behaviors. The CITE program helped them work on this and the parents said it was a great relief to be able to sit down at a dinner table and eat together as a family. Some of the families also had problems outside the home. Derrick Harding told me: "We have a problem with Eric's behavior when we go out as a family. Up until a month ago we didn't go out anywhere. Now CITE is working with us once a week on outings." Ellen Spencer said: "CITE gave us the confidence to take Paul out to dinner. The trainer went with us and we ate as a family out at a family-type restaurant and we had never done that before." She expressed a great relief that they were able to function more like a normal family.

Emotional Support

Some of mothers told me that the most important thing with the CITE program was the emotional support the trainer provided them. Ellen Spencer said: "It is a lot more than just coming into your house and teach you some skills. It is also someone to sit and listen, and to comfort you when you cry." Another mother told me that the CITE trainer had given the whole family much needed emotional support and added that this had been a "serendipity of the program." On that point

she seemed to be right because the program coordinator told me that the trainers: "... should be close to the family but not too close. They should hold a professional distance."

Dealing with Challenging Behaviors

Many of the children involved in the CITE program have problematic behaviors and the trainers rely heavily on behavior management as a way of teaching the parents how to deal with their children's behaviors. As a result the trainers teach the parents diverse behavioral techniques, like to "time out" the children. (Time out means that the child is removed from a situation into a neutral setting for a short time.)"

Another aspect of this approach is that the program requires the parents to "take data" on their children's behaviors. Some of the parents resist this approach to dealing with their children. One of the mothers told me: "I hate taking data, data taking is terrible. When I sit down with my son I hate to count how many times he plays with this or that. I'm running a home and I feel it is too professional."

Many of the parents were not critical of these techniques and saw them as an effective and professional way of dealing with difficult situations. But a few of the parents were uncomfortable with this and some of the mothers told me that they had difficulties "timing out" their children.

Defining "the Family" to Work With

Janet Lee is one of the black single mothers the program is working with. Her son Frank is 4 years old and has mental retardation, a communication disorder, and challenging behaviors. When Janet and Frank became involved with the CITE program they were living in an extended family; with Janet's parents, brothers, a sister, and the sister's baby. The CITE program saw the collective effort of this extended family in dealing with the problematic behavior of the child as an interference with what the CITE program was trying to accomplish. CITE staff therefore encouraged Janet to move away from her extended family and establish her own home with Frank. Janet followed their advice and is now living alone with her son in what the CITE staff describe as a "bad" neighborhood near downtown Cincinnati.

ISSUES AND DILEMMAS

As concluding remarks I would like to reflect on some of the issues and dilemmas the agency was struggling with at the time of the visit.

First, as an agency, RHMR does not have an ideology that everyone agrees on and people within the agency have different and conflicting ideologies. The ideology behind the CITE program conflicts with the agency's long term commitment to provide residential services for children. This is a major problem within the agency and there does not seem to be a solution in sight in the near future. There are still many people within the agency who believe that there will always be children who need residential placements in group settings and do not want to scale back or close

the West Fork Educational Center. People within the agency need to come to an agreement on one ideology, otherwise it is very hard for the agency to have a clear sense of direction. Some of the leaders within the agency had hoped that the CITE program would help influence changes within the agency. This has come true and the CITE program has had an impact on people. At the same time, for the program to be successful in supporting families to care for their children with disabilities at home, the agency needs a strong ideological commitment that says that all children with disabilities belong in families.

Second, the focus of the program. The agency wanted to get their foot in the door with the CITE program to "prove" to people that family support was a good idea. They started with a time-limited program that was narrowly focused because they wanted to be able to show some success. The agency has certainly managed to show success and has convinced many people that this kind of a program is a very good way of serving families. After this initial demonstration period is over the agency might want to consider broadening the focus of the program. The supports families need and/or want can vary considerably from one family to the next. Some families may only need time-limited intervention, others may need constant and on-going support. Some families may need only one type of support, others may need several. And families may need more intensive supports during certain times and less intensive supports at others. The CITE program may want to broaden its range of services and reconsider the time-limitation of the program to be able to better meet the different needs families have and be able to vary these services as the needs change.

Third, the CITE program might want to make a stronger commitment to the families in need of their services. Many family support programs have a commitment to do "whatever it takes" to support families of children with disabilities to keep their children at home. The CITE program does not share this attitude towards families. On the contrary, program staff told me that they "gave up" on some of the families because they saw them as hopeless. One of the staff said: "We can only do so much." At the same time, the families which CITE staff gave up on seemed to be the families that most desperately needed help. Among these were families where the mother had limited intellectual abilities or a history of mental problems.

Fourth, the dilemma between maintaining a professional distance and providing emotional support to families. The agency's administrators and the CITE coordinator have a strong emphasis on professionalism. One aspect of this is that the trainers are expected to keep a professional distance from the families. At the same time, many of the families told me that the emotional support provided by the trainers was the most important component of the program. In the light of this dilemma the agency might want to rethink its emphasis on keeping a professional distance from the families.

Fifth, some of the behavior management techniques employed by the program do not "fit into" a regular family life. As a result some of the parents seemed to have the feeling that their home had been turned into a training program. In the light of how some of the parents feel about these issues, program staff might want to reconsider their basic approach to dealing with difficult behaviors. The parents might be more comfortable if the program used the non-punitive, positive approaches that

}are by many seen as a more humane and more effective way of dealing with challenging behaviors (see for example, Evans & Meyer, 1985; Lovett, 1985; McGee, et al., 1987).

Sixth, how should a family support program define "the family" they are working with? The example of Janet Lee and her son, Frank, raises this question most clearly in relation to the CITE program. The CITE program seems to have a narrow definition of a family in mind, and in Janet's case the CITE program staff defined Janet and Frank as "the family." Maybe it would have been more appropriate to define Janet's extended family as "the family" to work with and support the extended family, instead of encouraging Janet and Frank to move away from them?

CONCLUSION

The Cincinnati area does not have many innovative integrated services and there is a great deal of resistance against any attempts to change the service delivery away from traditional segregated services. As an agency RHMR has managed to create an innovative program in a very hostile environment. Such changes are very difficult and can only come about where there is committed leadership. One of the intents of the CITE program was to establish a good integrated family support program that would have teaching value and serve as a model for further changes in the area. This has been the case and the CITE program has become a rallying point for a group of parents and professionals in Cincinnati who are interested in creating integrated services.

There are a lot of good people around the country who are struggling to create changes in the way we deliver services for people with disabilities. Some of these people have managed to create changes under very difficult circumstances. This report has highlighted the struggles of one of these places.

NOTES

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REFERENCES

Agosta, J., Bradley, V., Rugg, A., Spence, R., and Covert, S. (1985). Designing programs to support family care for persons with developmental disabilities: Concepts to practice. Boston, MA: Human Service Research Institute.

Evans, I., & Meyer, L. (1985). An educative approach to behavior problems: A practical decision model for intervention with severely handicapped learners. Baltimore, MD: Paul H. Brookes.

Lovett, H. (1985). Cognitive counseling and persons with special needs. New York, NY: Praeger.

McGee, J., Menolascino, F., Hobbs, D., & Menousek, P. (1987). Gentle teaching: A nonaversive approach for helping persons with mental retardation. New York, NY: Human Sciences Press.

RHMR. (1987). C.I.T.E. Community integrated training and education: An alternative to facility-based services. Cincinnati, OH: RHMR.

Taylor, S. J., Racino, J. A., Knoll, J. A., & Lutfiyya, Z. (1987). The nonrestrictive environment: On community integration for people with the most severe disabilities. Syracuse, NY: Human Policy Press.